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Dress to Impress: Parents' Fears of Allegations of Fabricated Induced Illness in Cases when their Child has Mitochondrial Disease - Exploring the Voices of MITO Families Ireland.

Phil O'Sullivan

CARL Research Project
in collaboration with
Mito Families Ireland



Name of student(s):	Phil O'Sullivan
Name of civil society organisation/community group:	Mito Families Ireland
Name of community group liaison person:	Tammy Meehan
Academic supervisor(s):	Dr Fiachra O' Suilleabhain
Name and year of course:	Master of Social Work, Year 2
Date completed:	19 th April 2018

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Community Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grass roots groups, single issue temporary groups, but also structured community organisations. Research for the CSO is carried out free of financial cost by student researchers.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

What is a CSO?

We define CSOs as groups who are non-governmental, non-profit, not representing commercial interests, and/or pursuing a common purpose in the public interest. These groups include: trade unions, NGOs, professional associations, charities, grass-roots organisations, organisations that involve citizens in local and municipal life, churches and religious committees, and so on.

Why is this report on the UCC website?

The research agreement between the CSO, student and CARL/University states that the results of the study must be made public through the publication of the final research report on the CARL (UCC) website. CARL is committed to open access, and the free and public dissemination of research results.

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Abstract

This study explores parents' fears of fabricated induced illness in their children who suffer from a mitochondrial disease. The paper will focus on understanding and appreciating the many concerns associated to parenting a child who suffers from a rare life limiting disease, an exploration of the role social work has played in their lives is also a focus of this research. The fear of false allegations of fabricated induced illness exacerbates the complexities already involved in parenting a child with a rare disease. The research implemented small-scale qualitative interviews with three mothers from the collaborating community group 'Mito Families Ireland'. The qualitative method enabled a thorough and descriptive review of the issues parents experience when their child has a mitochondrial disease. The absence of literature further complicates the area, thus it was essential to utilise primary research methods which gave in-depth analysis of such a complex and contested area for parents and professionals alike. The results paint a negative portrayal of social work, as well as the parent-professional relationship when a mitochondrial disease is involved. Furthermore, the parents highlight the role of social work whilst describing its perception amongst parents in contemporary Ireland. An emerging theme provided the inspiration for the title of this paper, where the notion of 'power dressing' was both a unique yet fascinating insight into the parent-professional dynamic. A variety of recommendations were offered in concluding the paper, where the implications for social work practice were briefly outlined. It is envisaged these recommendations may inform policy and practice moving forward

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Introduction:

Chapter One

- Introduction
- Title
- Background
- Rationale
- Aim of the Research
- Objectives
- Research Questions
- Definitions
- My Reflexive Positioning as the Researcher
- Chapter Outline

Introduction

The overall research question poses a rare yet valuable opportunity to gain a better understanding of what can be such a complex and contested topic. This particular research title has been designed in collaboration with MITO Families Ireland, a voluntary organisation aimed at raising awareness and providing continued support to families affected by mitochondrial disease. Mito Ireland (2017) suggest that *“allegation or suspicion of Fabricated Induced Illness (FII) tends to be viewed with shame and fear yet in the case of rare diseases does not appear uncommon. No research related to this issue and mitochondrial disease has been undertaken in the Irish context”*. It is envisaged that this research may highlight an issue which has been overlooked in many social and professional aspects, particularly in relation to Ireland. It is anticipated the completed research will give a voice to the minority and potentially raise awareness of this issue on a broader scale. Considering the significant gaps in Irish literature and policy, it is hoped the research may inform professionals of those who experience FII in families affected by mitochondrial disease (Mito Ireland, 2017).

1.2 Title

Dress to Impress: Parents’ Fears of Allegations of Fabricated Induced Illness in Cases when their Child has Mitochondrial Disease - Exploring the Voices of MITO Families Ireland.

1.3 Background

This research question is in conjunction with CARL (Community Academic Research Links). *“Community-Academic Research Links is an initiative in UCC which provides independent research support to Civil Society Organisations in the region. The research is undertaken by students in collaboration with the community partners across a wide range of disciplines”* (UCC, 2017). The study looks to examine parents’ fears of allegations of fabricated induced

¹ Fabricated Induced Illness (FII) is explained in section 1.9.1

illnesses in their children who suffer from mitochondrial disease. Many key questions have been raised by the collaborating group, MITO families Ireland. This particular topic can be rather complicated in terms of gaining an understanding and appreciation of both the broader area of mitochondrial disease and the specific question of fabricated/induced illness (FII). The background to this research proposal aims to gain a better understanding into parents' fears of allegations of FII, specifically focusing on those whose children suffer from mitochondrial disease. Mito Families Ireland suggest there is a constant fear and a sense of guilt noticed in the relationship between FII and mitochondrial disease.

1.4 Location of the Research in Current Literature

Mitochondrial disease is a rather new topic in terms of understanding the social and personal element involved. Literature focusing on this diverse area is extremely rare. Given the social aspect of the research it is rather difficult to locate viable knowledge and information related to the research. A focus has always been placed on the scientific skeleton which shapes mitochondrial disease, and this is where the majority of literature can be located.

1.5 Rationale

The study looks to critically analyse what is Fabricated Induced Illness and examine the resulting negative factors it has on parents through fear of allegations. This particular research has been requested by a number of members of Mito Families Ireland. The research will explore parent's experiences of professionals and their experiences of fabricated illness. Furthermore, it is believed that this information would be beneficial to the National Office for Rare Diseases as it is a relatively new office.

1.6 Aim of the Research

The overall aim of the research project is to understand parents' fears of false allegations of FII when dealing with a rare disease such as mitochondrial disease. The research questions

have been created to gain a transparent understanding of such new and often challenging times for some families in our society.

1.7 Objectives:

The study looks to critically analyse what is Fabricated Induced Illness and examine the resulting negative factors it has on parents through fear of allegations. The study hopes to raise awareness of such a contested topic in society and close the political and legislative gaps that are apparent in contemporary Ireland. It is expected that this research will expose an issue which tends to go undiscussed in many circles within this country. It is anticipated this research will give a voice to their experiences and could potentially raise awareness of this issue on a wider scale and inform professionals as to the experiences of the families who suffer as a result. The issue of alleged fabricated illness is in relation to professionals dealing with parents.

1.8 Research Questions

1. What is Fabricated/Induced Illness and how does it relate to the experiences of parents who have children with mitochondrial disease?
2. What factors lead to fears of suspicion/allegations in cases of children with mitochondrial disease and what are the personal/social/health implications of this concern on parents and families?
3. What are parents' experiences of professional supports and service provision and what is the role of social work?
4. How do these parents' experiences correspond with contemporary debates about user participation and empowerment in health care and social work provision?

1.9 Definitions and Concepts

A number of key terms are the focal point of this research project. These shall be briefly outlined below.

1.9.1 Mitochondrial disease

Mitochondria cells are responsible for creating more than 90% of the body's energy needed to survive (United Mitochondrial Disease Foundation, 2011). The term “mitochondrial disease” is not a single disease, however, it is an umbrella term used to describe a wide range of genetic disorders that arise due to mitochondrial malfunction in the body. According to Senger, et.al.,(2016), failure of the mitochondria to perform normally results in decreased energy production, cell injury or cell death, and eventual organ dysfunction or failure. Symptoms of mitochondrial disease may appear at any time where they are often progressive and extremely debilitating. Unfortunately, establishing a clear diagnosis for mitochondrial disease has been extremely difficult. Many parts of the body can be affected by the disease, including the central nervous system, skeletal and muscles systems to name just a few (Dassler and Allen, 2014). A rare disease affects “5 in 10000” of the population (NRDP,2014:12). It is unconfirmed how many cases of mitochondrial disease have been confirmed in the Republic of Ireland. Contact was made with the National Office for Rare Diseases (see appendices), however, they were unable to provide any statistics.

1.9.2 Fabricated Induced Illness (FII)

Understanding FII can be rather difficult as there is no universal definition. However, the explanation given by the National Health Service in the United Kingdom gives a clear and concise outline of the often-contested term. It states “*Fabricated or induced illness (FII) is a rare form of child abuse. It occurs when a parent or carer, usually the child's biological mother, exaggerates or deliberately causes symptoms of illness in the child*” (NHS, 2017). Up until recently, FII was commonly known as Munchausen Syndrome By Proxy (MSBP). Due to the limited research containing the more recent term of ‘Fabricated Induced Illness’ some

literature may include the previous term of ‘Munchausen Syndrome By Proxy’ (MSBP). However, for the purpose of this research, FII shall be used where possible.

1.10 My Reflexive Positioning as the Researcher

To avoid bias and ensure a level of transparency throughout the research, it was important to outline my reflexive positioning with the research process. Through such acknowledgment, it will provide a level of fairness and credibility to the findings (Mays and Pope, 2000). Considering the researcher has no connections with the community organization, it is hoped bias and prejudicial findings or discussions shall be avoided throughout the research. The reflexive position maintained within this research has been shaped by principles of equality, honesty and professionalism when undertaking primary research.

1.11 Chapter Outline.

Chapter One

Chapter one shall introduce the main topic which will form as the basis for this research thesis. Pertinent aspects such as background, current literature and associated key terms will be also addressed here. The aims and objectives of the research combined with the overall research questions will be clearly outlined in this chapter.

Chapter Two

This chapter consists of a literature review which will critique crucial elements attached to the area of FII and mitochondrial disease. The review will provide a structure to the overall research whilst informing the researcher what the existing literature can offer in attempting to understand the research question

Chapter Three

Chapter three outlines the methodological approach whilst discussing the philosophical and theoretical positing which underpins the research. The qualitative research approach will be discussed as will the data collection methods which were implemented within this project. A brief review of the ethical procedures shall also be outlined.

Chapter Four

Chapter four presents the findings which arose from the in-depth semi-structured interviews. Key themes emerged from the interviews and these shall be discussed with the correlating literature and associated research questions

Chapter Five

The final chapter concludes the research findings and presents a number of recommendations moving forward. These shall include social work practice, professional domains of medical professionals and national policy regarding the treatment of rare diseases. A brief reflective piece shall also be included in this final chapter

Chapter Two

- Introduction
- Mitochondrial Disease
- Fabricated Induced Illness (FII)
- A Unique Relationship? FII &
Mitochondrial Disease
- False Allegations
- Model of Care: Finding the Balance
- National Policy: An Irish Context
- Conclusion

2.1 Introduction

Transparency and insight relating to mitochondrial disease and fabricated induced illness (FII) is scarce amongst current literature. According to (Rabonne et al, 2014:1) “*one of the most challenging situations for a paediatrician is to recognize a fabricated or induced illness in a child*”. The lack of clarity surrounding FII only exacerbates the identification and management process of children who also suffer from a rare life limiting disease (Lazenbatt, 2013). There is a significant gap in relevant literature, especially literature within an Irish context. This gap can have detrimental consequences for families whose children are suffering from a mitochondrial disease. Whilst medical and scientific literature around mitochondrial disease is being promoted, the social aspect of those affected by mitochondrial disease has been ignored. This study will aim to shed a new perspective on the social and psychological impacts which are associated with mitochondrial disease and accusations of FII. A clear and concise review of the literature will provide the framework upon which this study can be based.

This review will focus on several key themes associated within the overall research questions which underpin this study. Firstly, the influencing theories and frameworks of mitochondrial disease will be examined, followed by gaining an understanding of the complexities associated with fabricated induced illness. A critique of the relationship between the two will subsequently be carried out, as well as an examination of false accusations and the negative consequences of such actions. Finally, the contrasting perspectives regarding the models of care of healthcare professionals in such cases will also be outlined in this literature review. It is envisaged this literature review will compliment and facilitate the overall goal of the research study.

2.2 Mitochondrial Disease

Having defined Mitochondrial Disease in the first chapter (Section 1.9), it is now imperative to gain a greater insight into the intricacies which are associated with the term. Diagnosing mitochondrial disease is an extremely complex and tedious process which often creates more questions than answers. Professional diagnostic language frequently consists of ambiguous jargon that offers little to no clarity when dealing with mitochondrial disease symptoms (Haas et al., 2007). As a result, children who suffer from a mitochondrial disease can have

complicated clinical diagnoses which further encapsulates the frustrations and confusion commonly associated with the disease, particularly for parents. Oftentimes, children with a mitochondrial disease can appear healthy and normal at birth:

Prognosis is highly dependent upon the type of disease, extent of organ involvement, and severity of clinical symptoms. Some children may experience only a few symptoms, such as severe fatigue, while others have numerous and severe chronic health problems or premature death (United Mitochondrial Disease Foundation, 2011).

Such a variety in clinical manifestations and general vagueness/ambiguity surrounding the disease makes a transparent diagnosis difficult for medical professionals. Such confusing factors may create a considerable amount of stress and negativity for parents and professionals alike. Parents whose children have mitochondrial disease often carry extraordinary burdens and “*face a complex array of responsibilities and challenges*” (Ray, 2002:435). There is no treatment for mitochondrial disease, and very few doctors are specialised in the area of mitochondrial disease, both in Ireland and internationally. The progressive nature of the disease can create emotional stresses on the family, particularly on the parents who are expected to advocate on behalf of their child when they are newly diagnosed. The child may present as being fine initially, however, over weeks, months or years the symptoms can dramatically worsen. It is this uncertainty which can have a heavy impact on the parent of a child with a mitochondrial disease. Hinojosa et al.,(2005) suggest caring for a child with a life limiting illness may create severe physical, emotional and social demands as a result of the intense level of care required.

2.3 Fabricated Induced Illness (FII):

As seen in the previous chapter, FII is a term which often has a sense of ambiguity to its meaning, particularly amongst medical professionals. A clinical report commissioned by the American Academy of Paediatrics in 2013 succinctly captures the vagueness associated with the term:

Although caregiver-fabricated illness in a child has been widely known as Munchausen syndrome by proxy, there is ongoing discussion about alternative names, including paediatric condition falsification, factitious disorder (illness) by proxy,

child abuse in the medical setting, and medical child abuse (Flaherty and Macmillan, 2013: 590).

Such an array of terms further complicates the review of credible and applicable literature as well as evidence attached with real life cases. However, for transparency throughout the research project and this literature review, the term “Fabricated Induced Illness” (FII) will be applied. As mentioned earlier, FII is a rather new concept, and it has replaced the medical term Munchausen Syndrome by Proxy (MSBP). Interestingly the Health Sector Executive (HSE) in Ireland outlines its stance on the varying terminologies associated with FII. It describes why the term FII is more suitable when examining contemporary cases. It succinctly differentiates between FII and MSBP as it suggests:

FII is also known as Munchausen syndrome by proxy. The term Munchausen syndrome by proxy is sometimes used to describe when someone fabricates or causes illness or injury to others. However, some healthcare professionals prefer to use the term fabricated or induced illness for two reasons... Munchausen syndrome by proxy places the emphasis on the person carrying out the abuse rather than the child who is the victim of abuse. The term Munchausen syndrome by proxy has been misinterpreted as a psychiatric diagnosis when, in fact, it was designed to describe a particular pattern of abuse (HSE, 2016).

Fish et al. (2005) also believe FII is a more suitable term as it places the focus on the pattern of behaviour and not on a psychiatric syndrome which may be present. Having gained a greater understanding into the two key terms of mitochondrial disease and FII, the unique relationship between the two and their relevance to this research will now be examined and discussed in greater detail.

2.3.1 A Unique Relationship? FII & Mitochondrial Disease

It appears that both FII and mitochondrial disease are complicated phenomena, surrounded by confusion, ambiguity and differing professional opinions and definitions. As a novice researcher in rare diseases, there seems to be an imminent sense of disadvantage towards the parents of those with a mitochondrial disease, where its blurred definition may leave parents susceptible to questioning or allegations prior to any professional meeting or assessment. Fish, et al. (2005: 1) suggest “*Professionals typically begin to suspect that a carer has fabricated or induced an illness in their child when children are repeatedly presented to*

medical practitioners or hospitals with difficult to explain illness symptoms". One cannot deny the difficulties associated with mitochondrial disease and it must be acknowledged there is a diagnostic challenge for professionals who are treating such rare medical cases. However, there may be some credibility to the suggestion that allegations of FII can emerge when professionals are dealing with a rare or unknown illness such as mitochondrial disease. The ever-present complexities and irregularities associated with diagnosing mitochondrial cases may create such assumptions amongst medical professionals. As a result, it may be possible for parents to experience FII due to lack of professional knowledge and clarity surrounding mitochondrial disease and its underlying symptoms which are so intricate and complex (Kreig, 2016).

It can be argued the lack of communication amongst professionals combined with the complexity of the condition only increases the likelihood of a parent/carer of a mitochondrial sufferer being accused of FII. To highlight an example where lack of communication and knowledge surrounding mitochondrial disease was present, a quote from University of North Carolina's Law Professor, Maxine Eichner, captures a common trend noticed in the precarious relationship between FII and Mitochondrial disease. Eichner (2015: Para 1) writes:

Jessica and Sean Hilliard of Attleboro, Mass., went through the agony of watching their 5-year-old son die in 2011 from what two outside specialists concluded was a genetic disease that affected mitochondrial function. A hospital paediatrician specializing in child protection, citing a pattern of behaviour that she contended suggested abuse, accused the parents of fabricating their son's medical issues, though she had not spoken with his outside doctors and therapists.

The relationship between FII allegations and mitochondrial disease has only been highlighted in recent years. According to a comprehensive article in the American Journal of Medical Genetics, *"The field of mitochondrial disease has only developed over the past 25 years, and clinicians have limited but growing evidence to formulate clinical decisions regarding diagnosis, treatment, and management"* (Parikh, S. et al., 2015:689). As a result, communication between professionals is crucial in seeking clarity and a diagnosis for any patient who suffers from a rare life-limiting disorder. The onus needs to be on the promotion of shared knowledge through improved communication, where relationship building is key.

False allegations of FII bring an element of frustration for the parents seeking medical treatment. The features of FII align heavily with symptoms of Mitochondrial Disease. The

sheer ambiguity of the illness and its unpredictability make it extremely difficult for parents to gain diagnostic clarity from medical professionals. The diagnostic challenges of mitochondrial disease, combined with limited knowledge, literature and impetus regarding its social impact means the FII and mitochondrial relationship is a fiercely contested one. The possibility of gaining an Irish perspective on this matter is something that is both exciting and necessary within the Irish medical sphere.

2.4 False allegations

Caring for a child with a rare life limiting illness will always place added stress to those involved, both from the child's perspective and the parents. Research conducted in the United States suggest *"parents of children with mitochondrial diseases experience significantly greater caregiver burden in the form of stress, anxiety and depression compared to parents of children with other metabolic diseases. This leads to poorer quality of life and social functioning for the caregiver and the family"* (Sofou, 2012: 3). Given the severe social and psychological burdens which accompany caring for a child with a mitochondrial disease, further stress and worry is not advisable. Unfortunately, false allegations of FII will heap more worry on those being accused. The psychological trauma which follows a false accusation of any kind can be extremely damaging. The resulting emotions may be aggravated when children are involved, especially if the accused is a parent or family member. Famous football manager David Jones² was falsely accused of abusing his child, with the resulting psychological trauma permanently etched on his mind. Mr Jones states in his autobiography:

what those who sought to convict me did was take away something that I will never get back; my dignity. The whole experience felt like a dagger being continually stabbed through my heart. [...] What I can never correct is the period of my life that was wrecked by the most horrific allegations any loving father could possibly face (Jones, 2011:221).

Such a raw and honest description gives the reader a brief insight into the trauma which accompanies false accusations. Medical cases involving a rare disease can often increase the chances of false FII accusations. According to Gortze (2015), many doctors lack the time to

^{2 2} David Jones is an ex-professional footballer turned professional manager from the UK. Mr Jones was falsely accused of child abuse in 1999.

gain an insight into rare conditions such as mitochondrial disease. Interestingly, Gortze goes on to suggest some doctors may feel threatened if a patient has a greater understanding of a mitochondrial disease and it is indeed a combination of these which “*create an unfavourable environment for patients and families seeking medical care for mitochondrial diseases*” (Gortze, 2015:5). The term ‘unfavourable environment’ is open to deliberation and may suggest a number of possible interpretations when dealing with a rare disease and FII. From the literature presented by Gortze (2015) it appears the ambiguity of both mitochondrial disease and FII may increase the chances of false allegations for the families involved.

To better understand the psychological affect FII and mitochondrial disease has on parents, it can be useful to include other rare diseases for comparison. Such a comparison was conducted by Read (2003) which suggests FII and mitochondrial disease:

When compared to mothers of children with PKU³, another inherited metabolic disorder, mothers of children with mitochondrial disease suffered greater strain and worry, their children required a significantly greater number of health care services, such as the involvement of more specialists and more hospitalizations, and overall these families experienced increased financial burden (Read, 2003:181)

FII and rare disorders such as mitochondrial disease have detrimental effects on the family. Needless social and psychological trauma combined with the extreme financial stresses of fighting a mitochondrial disease are prohibiting factors for the families involved. In extreme circumstances, depression anxiety and rage have pushed the parents or caregivers beyond their limits due to the burdens being placed on them (Avison et al.,1999). The literature points to significant adverse consequences from a personal, social and financial perspective (Hughes and Waite, 2012).

2.5 Model of Care: Finding the Balance

It is imperative to identify the connection between mitochondrial disease, FII and a model of care which is appropriate for the circumstances. From the literature we can appreciate the complex and contested relationship which accompanies the topic. As a result, the designated treatment, and services available to families battling a mitochondrial disease is of significant importance. It has been suggested that parents of those who are affected by mitochondrial disease are often forced to become the ‘experts by experience’ in the illness. (Mito Families

³ Phenylketonuria (PKU) is a rare but potentially serious inherited disorder. Our bodies break down protein in foods like meat and fish into amino acids, which are the "building blocks" of protein (NHS, 2017)

Ireland, 2013). That is, use of their own initiative in seeking information around the assessment of symptoms. This enables the parent to gain extensive knowledge of the disease in question. Similarly, it has been stated “*empirical research shows that in rare diseases, due to the low prevalence and the lack of expertise, the patient is forced to become knowledgeable about his own disease*”. (Budyk et al., 2011: 154)

Such a belief would suggest the need to increase and develop collaboration amongst professionals and parents when attempting to determine a case. The lack of training and information made readily available to medical professionals is a concern for those battling a rare life limiting disease. A comprehensive approach which promotes empowerment and participation from the parent’s perspective may yield optimal results for the patient. Identifying a balance between the forensic/medical approach and a systematic holistic approach is necessary if the best care of the child is to be provided. There needs to be more collaboration with parents in cases involving rare disease.

Because a rare disease affects every aspect of their daily life, patients and their caregivers become experts of the rare condition and of the important outcomes of diseases that need to be addressed. It is thus critically important to partner with and listen to them (Bronstein and Kakkis, 2016:731).

When discussing the importance of patient focused care and treatment for rare diseases, Dr. Janet Woodcock, Director of the Centre for Drug Evaluation and Research (CDER) at the U.S. Food and Drug Administration (FDA) states:

It is clear you have to start with an understanding of the impact of the disease on the people who have it, and what they value most in terms of alleviation before you set up a measurement and go forward with truly patient focused drug development (Woodcock, 2015:4).

Though it is not directly related to rare diseases as such, Dr Woodcock highlights a poignant aspect of medical service provision. The inclusive approach may capture the social factors which have been absent in terms of understanding mitochondrial disease. This is where a holistic model of care would possibly benefit both the parents and professionals involved, provided communication was a core value which was accepted across the board.

2.6 National Policy: An Irish Context

A National Rare Disease Plan (NRDP) was launched by the government in 2014 and is the only guideline for information on managing rare diseases in the Republic of Ireland (Minister for Health, 2014). There is no specific legislation relating to mitochondrial disease in Ireland, where a significant legislative gap is present. The NRDP was established due to a recommendation made by the EU council in 2009 which suggested more knowledge and information around rare diseases needs to be implemented. The NRDP is driven by a steering group made up of stakeholders from patient organisations, state agencies, the Health Service Executive and the Department of Health (Minister for Health, 2014). An interim report on the policy implementation highlights the progress made by the report. The NRDP have identified excellent goals and objective in the plan, however, as the interim report points out, many of these have yet to be implemented within current policy. A new and updated NRDP is scheduled for publication in 2019, however, no information can be currently found on this proposed plan.

2.7 Conclusion:

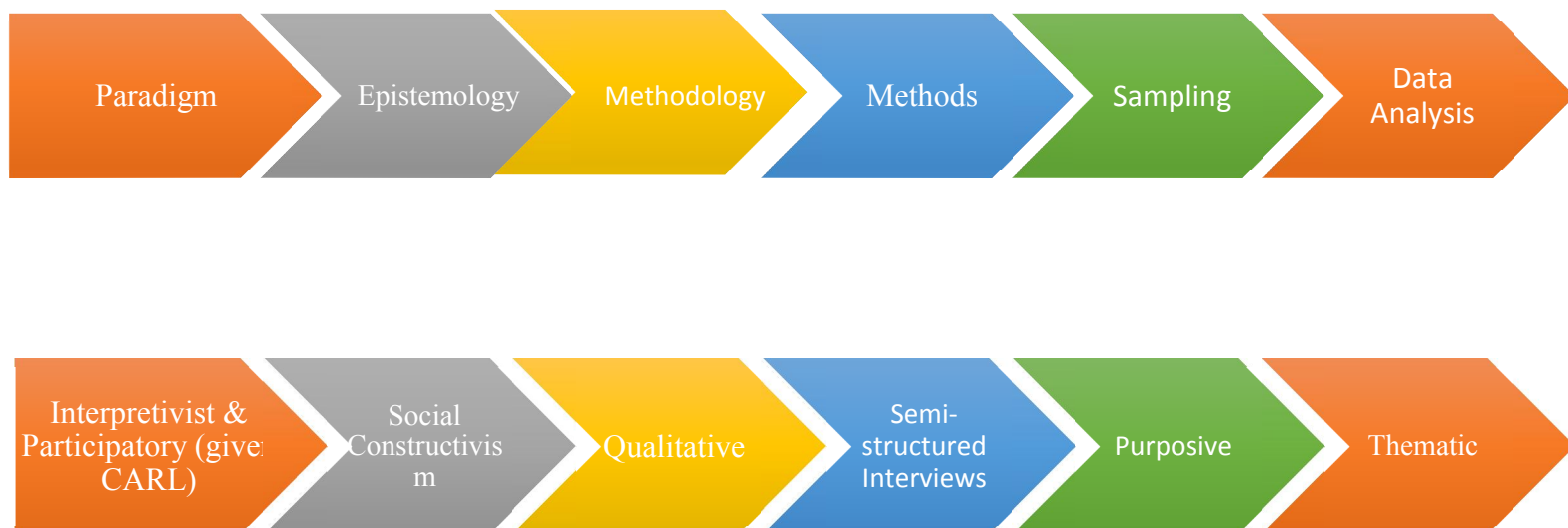
The vagueness and ambiguity associated with the key terms identified through this review only adds intrigue to the overall research question. A clear link has been noticed between mitochondrial disease and FII, where promotion and awareness raising of the term may help fill the legislative and political void which is clearly noticed within an Irish context. Both terms need to demand more respect, especially in the professional medical sphere. The allegations of FII appear to be extremely unfair to genuine carers of those whose child has a mitochondrial disease. The literature paints a bleak picture in terms of medical diagnosis for those who suffer from a rare disease. It is extremely difficult to have diagnostic clarity when the disease under examination is so difficult to comprehend. Such realities naturally lead to suspicions of FII, particularly with mitochondrial disease.

- Introduction
- Philosophical and Theoretical Underpinnings
- Epistemology
- Methodology
- Research Methods
- Sampling
- Data Analysis
- Ethical Considerations
- Limitations
- Conclusion

3.1 Introduction

This chapter will succinctly outline the methodology which has been implemented within the research design. An examination of the theoretical and philosophical frameworks which underpin this study shall also take place. A detailed review of the research, sampling, data collection and analysis methods will also be summarised within this section. To conclude this chapter, a clear description of the limitations associated to the research, as well as any ethical considerations which were present shall be outlined for the reader.

My Methodology



3.2 Philosophical & Theoretical Underpinnings

In 1781, Immanuel Kant published “The Critique of Pure Reason” which pioneered various theoretical approaches attached to qualitative research methods. Since then, many social scientists have placed emphasis and value on his findings which investigated “*human interpretation of the social world and the significance of both participants and the investigators interpretations and understanding of the phenomenon being studied*” (Ritchie et al., 2014:11). Kant’s focus on interpretivist thinking has created a framework which will be utilised throughout this paper and has given me as the researcher an opportunity to yield a

greater appreciation of what is being examined. Such a framework also facilitates creativity and opportunity to explore the complicated topic which is being reviewed throughout this paper. Furthermore, it gives the research a theoretical structure which brings a unique sense of professionalism and credibility to the research. In essence, *“interpretivism embodies and supports the core principles of both the life history approach, and qualitative research in general - emphasizing and allowing participants’ vocal accounts to take precedence while also contextualizing and framing these perspectives within a theory”* (Carey, 2009:152). The overall process was in collaboration with the community group Mito Families Ireland, who have played a key role in the successful completion of this research project. Implementing a participatory paradigm within this research created a unique sense of participation and empowerment for community members. Such values will yield positive results for their community group.

3.3 Epistemology

“Epistemology is concerned with ways of knowing and learning about the world and focuses on issues such as how we can learn about reality” (Ritchie et al., 2003 :6.). This research has adapted a social constructivist approach which suggests that perception and knowledge are “constructed or created” by humans as opposed to being objectively interpreted and received. (Ritchie, et al., 2004). Such an approach suggests that individuals maintain a unique outlook and perspective on society, where society is viewed completely differently by various people in various places. A constructivist viewpoint places emphasis on subjective experiences of people, thus suggesting humans construct their knowledge based on social, cultural and historical experiences (Creswell, 2014). Social constructivism will be implemented here to understand parents’ fears of allegations of FII in their children who have a mitochondrial disease. This epistemological approach will yield the most clear and in-depth results for Mito Families Ireland.

3.4 Methodology

Qualitative research aims to investigate how people experience the world whilst gaining a holistic perspective of the topic being reviewed. *“The researcher attempts to capture data on the perception of local actors, through a process of deep attentiveness, of empathetic*

understanding and of suspending preconceptions about the topics under discussion” (Miles and Huberman, 1994:6). This approach was implemented to gain a greater insight into parents’ fears of allegations of FII in their children who have a mitochondrial disease. Such an approach facilitated parent’s ability to critically engage with the research and use descriptive and free-flowing language to capture their thoughts, feelings and emotions. Qualitative research created the platform upon which the participants could include rich, descriptive and heavily contextualised descriptions which allows for a detailed review of the research topic (American Psychological Association, 2018).

3.5 Research Methods

Semi structured interviews are used to gain a holistic overview of the thoughts and feelings of the interviewee. You are there to learn about their point of view and gain a better understanding of an issue from their perspective. It was envisaged a semi-structured approach would be the most effective method to meet the aims and objectives of this research project. Conducting a semi structured interview *“demands a high very level of concentration and the ability to be very reflective and reflexive”* (Pickard, 2013:200). These are essential social work skills which had to be implemented due to the sensitive nature of the topic. In semi structured or in-depth interviewing, the researcher needs to be empathetic, show excellent listening skills whilst also following the participants lead during the interview. *“The process resembles a dance, in which one partner (the interviewer) must be carefully attuned to the other’s movements. Because the interviews are not prescribed, they can sometimes take surprising turns. Thus, in-depth interviews are particularly useful for exploring a topic in detail”* (Esterberg, 2002:87). This was a pertinent aspect to the research process, as the emotional responses of the participants often triggered other thoughts and insights. As a researcher, it was crucial to facilitate a space where the participants could engage with such emotional complexities associated with the topic. The descriptive nature of the responses, gave an unprecedented insight into parent’s fears of allegations of FII in their Children. A number of scholars have suggested that semi structured interviews are a useful method to research marginalized groups where key issues may be misrepresented amongst society (DeVault, 1990).

3.6 Sampling

The procedure of sampling involves the researcher selecting people or samples from the population prior to undertaking the research. For this particular research project, participants were selected through the implementation of a purposive sampling approach. Purposive sampling involves “*choosing a selection of individuals or groups based on specific questions or purposes of the research in lieu of random sampling and on the basis of information available about these individuals or groups*” (Tashakkori and Teddie, 1998:76). A Purposive sampling approach enables the researcher to select the participants based on specific characteristics of the study (Edmonds & Kennedy, 2012). It was the distinctive characteristics associated to the research topic which facilitated the decision to choose members within the Mito Families community group. This sample of research participants provided the study with ‘information-rich cases’ which could yield optimal results surrounding false allegations of FII and mitochondrial disease. “*Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research*” (Patton, 2002:169). It was envisaged the members of Mito Families Ireland would provide a thorough and insightful perspective into the research question being explored. Furthermore, seeing as this research topic is in collaboration with CARL and Mito Families Ireland, a purposive sample approach is conducive with the research study.

3.7 Data Analysis

In facilitating a true sense of active listening and a thorough investigation into a complex topic, the interviews were digitally recorded and sent away for professional transcription. The interviews lasted approximately one hour, with one interview lasting almost 90 minutes. Upon engaging with the interviews and from detailed analysis of the recordings, certain themes emerged from the interviews. Thematic analysis enables the researcher to observe various perspectives and interpretations. It gives the researcher a unique platform which provides a different focus on the information being discussed and observed (Boyatzis, 1998). In thematic analysis, the researcher focuses on “*what comes up in the data commonly and calls these themes, then using these as headings for writing up the research report. In some way or other the themes stand for the way ideas are organised in the minds of the people*

studied” (Gomm, 2008:10). As a result, it was envisaged thematic analysis would yield transparent results which could truly capture the voices of Mito Families Ireland.

3.8 Ethical Considerations

In completing this research, a variety of ethical considerations had to be outlined from the beginning. This was an integral element of the overall research process, due to the sensitive nature of the topic and the significant focus on primary research which would underpin this CARL collaboration. In order to undertake the research, ethical approval had to be granted by the Social Research and Ethics Committee (SREC)⁴ in UCC.

Confidentiality

Upon review of the recommendations of SREC, the researcher has reconsidered the interview process and determined that in order to maintain confidentiality, participants will be interviewed individually. This will ensure confidentiality and anonymity be maintained in an interview where both the father and the mother may be interviewed. The initial intention was to interview couples, however, the lack of male respondents combined with ethical considerations narrowed the scope of the research lens.

Psychological Trauma

There may be exposure to psychological trauma when responding to interview questions. The questions have been designed in a way that gives the respondent an opportunity to tell their story, which may bring up sensitive issues or memories. The contact person has been advised on possible issues arising from these interviews. The contact person in question is a qualified social worker and has adequate training if such circumstances arise. The name and contact details of this person have been identified on the information sheet

⁴ The Social Research Ethics Committee (SREC) is a panel of research professionals who determine if research is ethically viable. SREC predominantly reviews research where human interaction occurs (UCC, 2018)

Data Storage

The data I shall be storing will be a hard copy and electronic copy of the interviews that will be carried out with the participants. The data will be securely stored in a locked office in UCC, the electronic file will be protected through a password protected computer. The data will be stored for 10 years. Only the researcher will have access to these files, however the electronic copies will be sent to a professional transcriber for transcriptions. The transcriber will also sign a confidentiality agreement guaranteeing participant anonymity with regard to the transcriptions.

There will be no names mentioned throughout the interviews and anonymity will be guaranteed throughout. If any publications arise from this research, pseudonyms will be used, and anonymity will be provided throughout. For the duration of the research, physical copies of data will be kept in a locked filing cabinet and electronic copies will be retained on an encrypted laptop. In line with the current practice on the MSW programme, on completion of the research, physical copies of the data will be destroyed but an electronic copy will be retained by the research supervisor, Dr. Fiachra O Suilleabhain. This electronic copy will be destroyed after a ten-year period. The electronic copy will be stored by Dr Fiachra O Suilleabhain on a UCC NAS file.

3.9 Challenges & Limitations

One of the biggest limitations to the research project was the lack of participants within the study. Despite the initial interest, only three family members participated in the research. This raises an interesting question surrounding why most parents decided not to take part in this qualitative study. Such a shortage of participants placed an added emphasis on the parents willing to explore the issue in detail. It was feared these circumstances may possibly create the ‘Santa Clause Effect’ within this research project. The ‘Santa Clause Effect’ occurs when the researcher expects too much information from the respondent and as a result an air of unrest is created (Sarantakos, 2005). However, this was not the case as each of the participants proved more than willing to explore the sensitive nature of the research topic and

gave extremely descriptive accounts through each of the interviews. This had a significant impact on successfully analysing the research question. Time constraints and management of academic, personal and professional life was another challenge experienced throughout the research journey. Identifying the correct balance through such a hectic period highlighted the importance of goal setting and prioritising certain aspects of one's personal and professional life.

3.10 Conclusion

This chapter has outlined the methodology approach which has been implemented within this research. The qualitative nature of the research will yield rich and informative data that can be used in understanding the overall question in greater detail. Ethical considerations have also been outlined and various steps have been implemented to prevent any issues with this regard. A brief discussion around the challenges and limitations of the research have outlined the passion and commitment shown by both the researcher and participants in successfully completing the research. The findings and analysis of this research shall now be discussed in the following chapter.

Chapter Four

- Introduction
- Medical Services and Treatment
- Lack of Professional Knowledge & Training
- Becoming the Expert
- Professional Relationships
- Power Dress
- Living with a Mitochondrial Disease
- False Allegations of FII
- Social Work
- Conclusion

4.1 Introduction

This chapter is focused on presenting a clear and succinct analysis of the primary data which arose from in-depth semi-structured interviews. The participants in the study consisted of three mothers whose children have been diagnosed as having a mitochondrial disease. A variety of key themes emerged from the interviews and it is these themes which will be discussed in detail throughout this chapter. It is envisaged the thematic analysis applied to this research will provide clarity and transparency pertaining to the main research questions which have been outlined in chapter one. Due to the descriptive and thorough nature of the interviews, many associating factors were discussed in detail by the parents, thus, a variety of sub-themes have been outlined and shall be critiqued as part of this results chapter. To maintain confidentiality, the parents involved in the study shall be identified as respondent (A), (B) and (C). Pseudonyms have also been given to their children who they may have eluded to throughout the interviews. It is important to note the significant limitations which accompanied this research, namely the restricted word count which dramatically reduced the opportunity to explore other key themes in greater detail. However, it is hoped the discussions will still provide valuable outcomes which have been outlined in the findings below. The findings section represents a subjective view of the participants involved and this must also be considered when analysing the findings.

4.2 Medical Services & Treatment

The area of medical services and treatment to those with a mitochondrial disease was an overriding theme noticed throughout this research. The consensus surrounding this issue was one of immense frustration and anger. All the parents described in great detail, contributing factors which had left such a negative perception of medical services and treatments within this country. A key sub-theme which emerged from participant frustrations regarding medical services was a lack of competent knowledge and training of medical professionals in contemporary Ireland.

4.2.1. Lack of Professional Knowledge & Training

The subjective nature and lack of consensus surrounding a mitochondrial disease can easily create ambiguity amongst medical professionals. Oftentimes it is these contrasting professional opinions which create frustration and anger amongst parents whose children have a mitochondrial disease (Krieg, 2016). The lack of transparency surrounding mitochondrial disease was an extremely pertinent theme in terms of understanding the parent's perspective of medical professionals in Ireland. In describing her parental experiences involving professionals and mitochondrial disease, respondent (B), who had been unsuccessful in gaining a medical diagnosis for her child in Ireland, sought help from a mitochondrial specialist based in the USA. Dr Kendall, a world-renowned specialist in the area of mitochondrial disease was able to establish a clear diagnosis for the parent and her sick child. However, it was stated that Irish doctors refused to accept the diagnosis whilst also accusing the mother of fabricating the illness. When describing the emotions involved in receiving a clear diagnosis, respondent (B) said it was initially relief, *“only for the doctors here (Ireland) to point blank refuse to accept her diagnosis. The doctor then accused me of Munchausen's (FII) and stated this child does not have mitochondrial disease”*. From the interview, it became clear she was deeply affected by the false accusations and refusal to at least consider an expert opinion. The frustration was compounded by the fact there is no mitochondrial specialist based in Ireland. Respondent (B) further added:

forget about who's right and who's wrong. The advice Dr Kendall has offered is vast. Her knowledge is vast. And she's put down very carefully in several reports advice to give them (doctors) on what to do and what not to do. And they won't do it. They don't want to look like they're wrong and that's what it's all about. And in the middle is a child, and her care needs are not being met because of this.

Morel and Cano (2017:1) ask *“has the rare disease voice been lost in translation?”* Such a suggestion raised another pertinent question regarding the child who suffers from a rare disease, and whether or not they have also been lost in translation. Respondent (B) briefly mentions this in the above quote and it certainly highlights a crucial aspect of rare diseases, questioning where the care of the child sits amongst such an equivocal area of paediatric medicine. In prioritising the care of a child with a life-limiting disease, sometimes the parent takes control of the situation. It has been suggested that parents whose child has a rare disease

are “often the leading experts in their diseases” (NRDP, 2014:59). This contested area of rare medicine shall now be discussed in detail below.

4.2.2 Becoming the Expert

It has been suggested that the parents of a child suffering from a rare disease “are increasingly considered experts in their child’s care, specifically in how the particular condition is developing in their child, many parents come prepared to health consultations with information” (Fergie et al., 2015: 1332). Within this research, each of the respondents placed significant emphasis on needing to become the expert. An overriding theme emerged where parents were left with no other choice other than to seek extensive and in-depth knowledge of the disease through their own initiative. In referring to consultants, respondent (C) stated that “obviously they don’t know. But at the end of the day there’s no specialist in Ireland that can help you or tell you anything about mitochondrial disease, so it’s down to the parents to do all the research themselves. There’s nothing there.”

Interestingly, a consultant based in Dublin suggested respondent (A) had a better understanding of mitochondrial disease than some doctors who initially start out their medical career in paediatrics. Reflecting on this point, respondent (A) states “while my knowledge of the disease is, according to the consultant in Dublin, extensive and very good, he reckons I know more than doctors that start out in paediatrics was how he described it to one of his registrars”. This raises an interesting point, where a medical professional gives weight to the argument of parents having a better understanding of mitochondrial disease than some doctors in this country. Such a statement raises question marks into the level of knowledge and training provided for medical professionals who may come across mitochondrial disease in this country. However, this may not be surprising, as Ireland has one of the smallest markets in the European Union, where medicines for rare diseases are made available (Locatelli, et al., 2018).

All three participants have discussed the need to become ‘an expert’ in terms of mitochondrial disease. The difficulty in gaining a clear diagnosis and medical outline, immersed with the fear of losing their loved one to the disease are some of the influencing factors which prompt such actions by parents and caregivers. Respondent (B) suggests

There’s no mitochondrial disease specialist in Ireland and there’s very few doctors who understand the umbrella term of Mitochondrial disease and how it affects the

body. The doctors don't have the knowledge or the expertise or the specialists here to diagnose a mitochondrial disease. How are they going to look after somebody with it when they've very little knowledge?

It is only through such descriptive conversations with parents does one understand and appreciate the severity of the task they are faced with. It is important to also acknowledge the professionals who are working with the parents in an attempt to understand and overcome the aforementioned hurdles. The contested nature of the disease means further research needs to be implemented in order to truly appreciate the complexities attached with a rare metabolic disease.

As Facey et al. have pointed out '*there is a need to gain international agreement on the evidentiary requirements for clinical effectiveness assessments of rare diseases that is accepted by all stakeholders*' (Facey et al.,2014:417). Such transparency will yield optimal results for those involved. The diagnostic complexity surrounding a mitochondrial disease makes it difficult for medical professionals to present a clear and succinct diagnosis to families. A focus on developing the knowledge and training of professionals may improve clinical diagnosis for those who suffer from a rare disease.

4.3 Professional Relationships:

From interviewing the parents, a clear sense of frustration, anger, antagonism and hurt was portrayed in each of the descriptive discussions. The participants explained in detail how such feelings came to the fore. The language used by the parents was vivid and imaginative and captured the true essence of their emotions. From the parent's perspective, it appeared there was no relationship between medical professionals and parents of children who suffer from a mitochondrial disease. When asked to describe her experience of medical professionals in Ireland, respondent (B) stated:

In Ireland, oh my god, they're brash, abrupt, rude, ignorant, dismissive, power-hungry, horrible, horrible people that treat you terribly, treat you really appallingly. I've met maybe two very good doctors in the 12 years of attending specialists that I would have faith in, or I've felt they've listened to me and believed me.

Such an emotional response depicts a rather negative perception of the client-professional relationship for this particular participant. It appears an issue of trust was fundamental in

casting such a destructive perception of medical professionals in Ireland. Similarly, respondent (A) states:

I have zero trust in any of them (consultants) because I think they've broken it so often it's almost like a disease in itself. Because now I could be meeting the single most genius in genetics and I don't trust him or her and I don't hesitate in letting them know that they have to gain my trust

These descriptions give a brief snapshot into caring for a child with a mitochondrial disease. Important to note is the subjective nature of these discussions. The participants have detailed their personal experiences where interactions with medical professionals have left them hurt and misrepresented. Due to the sensitivity of topic, it can be difficult to depict the emotions in a way that doesn't implicate all doctors and specialists under this particular theme. However, it is crucial to improve the general parent-professional relationship, as the trust and belief created may influence positive outcomes for the child and improve the quality of medical care which is being provided (Goldstein and Wolfe, 2013). Communication is crucial to any relationship and becomes an integral component when dealing with a rare disease. It has been suggested in chapter two that doctors should embrace patient knowledge around the disease and work with the parent to achieve shared goals. The findings indicate some doctors undermine parents and their vast knowledge of mitochondrial disease. Respondent (A) succinctly captures this perception when she stated:

So if you dare walk into their (consultants) hospital with more knowledge than the guy that's treating you there is a certain element of who do you think you are, you're just the mother. You're considered a mental pygmy because you're a mother and you shouldn't be telling us what to do

Nichol et al., (2017) discuss the implications for health care practice when there is conflict between the parent-professional dynamic. The manner in which information is gained and shared was identified as being a key issue within this dynamic. As we have seen through this research, many parents are forced to become the expert. It now must be asked if this has created a sense of unrest between such a pertinent dynamic of the child's access to appropriate medical care. The parent-professional relationship has created a clear barrier for parents within this study, however, one method which is commonly used by parents to counteract the imbalance was the notion of 'power dressing'.

4.3.1 Power Dress

When someone is creating a first impression, the individual is influenced by nonverbal behaviours, this behaviour may be exacerbated when verbal behaviour or information is absent from the interaction (Gurney et al., 2017). Participants in this study described an interesting tactic which was implemented to boost confidence and create a sense of equality when first meeting medical professionals. Respondent (A) states:

I had to dress accordingly. I power-dressed. And that sounds like a ridiculous thing. You power dress for interviews, you power dress for meetings. I learned never to sit and let a doctor stand. I learned their language, I dressed in a suit always.

This suggests the participant may have felt undermined or minimised by medical professionals and this was her way of bridging that suggested divide. Respondent (B) described her perception of professionals, in this case specifically consultants, to be “*quite dismissive and looked down their nose at you. Really, really horrible. I felt small, nervous, physically sick going into some appointments*”. Respondent (A) also added that people in tracksuits and comfortable clothing, which would be common attire for lengthy stays in a hospital waiting room, “*didn’t get the same respect from doctors as the women wearing a suit and a pair of high heels*”. This subjective statement suggests the possibility of prejudice amongst those in positions of authority in the medical profession. It could be a valuable piece of research if it was conducted on a far greater scale.

Furthermore, respondent (B) suggests that she implemented a similar tactic and was “*dressed to the best, look pristine, know what you’re going to say, make eye contact, bring a notebook and pen and start writing down when they start talking. It makes them extremely nervous, but it also gives you a bit of power*”. Such behaviour indicates a presumption of inferiority when it comes to meeting medical professionals, this was strongly stated by all participants within this research. It has been suggested that “*patients have recognized that they are not passive recipients and are able to resist the power and expert authority that society grants doctors*” (Longnecker and Ha, 2010:39). From the findings, it appears the parents involved have identified some unique methods of engaging with the professionals in a respectable manner where the possibility of an inferiority complex has been minimised.

4.4 Living with a Mitochondrial Disease:

Parents of children with a rare or undiagnosed medical condition believe an absence in diagnostic clarity creates significant obstacles for those attempting to avail of services. It has been suggested children who receive a clear diagnosis will be much better placed to avail of appropriate services (Lewis et al., 2010). Living with a mitochondrial disease is not easy, and from this research it has become apparent that significant stress and emotions are immersed within the challenges of parenting a child who has the disease. Parents are constantly in the dark and the continuous absence of knowledge and information has such significant consequences for families. One mother described living with mitochondrial disease as:

A nightmare. Uncertainty. It's a label that was given, taken away, given, taken away and then given again...One minute she's fine and the next minute she's very sick, it's scary and very lonely. You don't know what's coming around the corner. You just don't know. And because the medical professionals don't know either you're just guessing. So, it's quite frightening. (Respondent, A)

Empirical research has identified that chronically ill patients prefer the medical professionals to facilitate and control medical proceedings such as provision of available services and information. However, due to the vague nature of mitochondrial disease, many families encounter medical professionals who have limited knowledge and understanding regarding this issue (Budysh, 2015). *“As a consequence for this perceived lack of expertise, parents felt they had no other alternative but to involve themselves in all aspects of their child's care and decision-making — something that they felt was emotionally stressful and difficult to do”* (Pelentov et al., 2016:15). This can be directly applied to the parents involved in this study. From the in-depth discussions, a variety of stressful emotions constantly appeared throughout. It became evident that living with a mitochondrial disease places an extreme burden on the family. One parent explains the frustrations attached with mitochondrial disease and its ambiguous nature, stating her desire for a more common disease with a clear medical diagnosis. Respondent (B) states:

God forgive me, it's an awful thing to say. I've wished for my child to have some known illness, even cancer, rather than this...at least they'll get the services. You'll get the respect. Your child will get the care. They'll be believed. It can be proved. It can be treated.

This quote poignantly captures the hurt and frustrations which many families experience. Mitochondrial disease takes over lives and often thrusts families into a cycle of despair which can be difficult to comprehend. It causes such pain to the children and their families, whilst

permanently etching a unique sense of confusion, annoyance and worry on their lives. According to Christabel and Helen (2016:78) “*Caregivers become anxious over issues like their child’s health, disability, disruption in their daily lives, stigma, death, spousal relationship etc. Caregivers can experience anxiety and stress when witnessing their children undergoes painful medical procedures*”.

The uncertainty for families involved can often be represented through social, medical or personal situations which constructs a sense of isolation for those in question (Brashers, 2001). It appears from the interviews that parents feel ignored and isolated when it comes to management of a mitochondrial disease. A sense of inferiority has been depicted through each of the interviews, this should not be the case considering how much of an ‘expert’ parents are forced to become. It could be advised that medical professionals implement a more inclusive model of care which promotes user participation and empowerment within the contemporary health care system. Parents in these circumstances may possess pertinent information relating to mitochondrial disease. A more holistic model of care, as described in chapter two, could drastically improve the overall relationship between professionals and families, but most importantly the medical outcomes for the child.

4.4.1 False Allegations of FII

False allegations of FII have left the parents involved in this research heartbroken and disillusioned. It is difficult to clearly capture such emotions through a limited research piece; however, a snapshot of their powerful stories will hopefully give the reader an insight into their difficult journey. Respondent (B) describes the impact false allegations have had on her life by stating:

I found it more frightening than my child’s diagnosis, than my child being sick. You spend your time worrying is somebody going to come to the door and whip the child away? You’ve all kinds of scary thoughts in your head. And the effect it has on your mental health-I’ve several times thought about taking my life; went as far as almost tried to. It’s a very frightening place to be, very, very frightening.

Such a powerful statement highlights the extreme negative impact these allegations can have on a parent whose child has a life limiting disease. The findings identify extreme social and psychological burdens which may be placed on parents a result. Interestingly, research carried out last year on mitochondrial disease suggests parents expressed similar fears when caring for a child who has a rare life disease. Meehan (2017), outlined the impact anticipatory

grief has on these families, where themes around powerlessness, uncertainty and fear became evident from the findings. It was indeed those findings which prompted further research in the area of mitochondrial disease, a clear psychological burden is evident across both research projects. It's not just those directly accused of FII who suffer the consequences of the false allegations. As respondent (B) highlights, the allegations directly impact the child involved. She states:

Because of the allegations made against me, on two occasions my child was brought into the hospital. They brought her in, my child was kept in a room for twelve days. Twelve days away from her family, friends, her school, her home, her little dog, all her little things around her, her routine. She hated it and she cried for most of the days she was there.

The false allegations have created an extreme sense of exhaustion and frustration for the families involved. At times, it appears the parents have almost given up and succumb to the pressures being placed on them because of the false allegations. A constant battle to highlight the disease with medical professionals has left these parents close to defeat. However, as respondent (C) points out, the parents have never, nor will ever give up fighting for their children. She states:

they were treating him so badly, and they treated me so badly. I was told I was using his condition as an excuse. I cried for two days coming out of the office and I'll tell you this much, nobody will ever put me and Matthew down like that again. I swear to god to this day I'm so angry. You will never, ever treat me like that ever again. But I was always a fighter obviously for Matthew but let me fight even harder. I said, 'You have a battle here' and a battle I won.

This quote aptly describes the constant battle which parents have experienced over the years. The allegations have put an incredible strain on these families. It is a strain which brings an extreme sense of anger towards those who make the false allegations of FII. One mother sought legal advice to clear her name. She describes how her solicitor advised her not to pursue legal action as she was only 'small fry'. Here, respondent (B) explains:

You're small fry, these are big fry. There's no point. You can't win. If you pursue this legally they're (The Hospital) not going to like you very much and you're not going to get the care and the nice treatment... We're just small fry fighting a system and the system is vast. It's medical, it's therapies, it's social work, it's all of those people, and you're just a mum and a child. You've no hope.

This quote succinctly captures the battle which parents are constantly facing with Mitochondrial disease. From the interviews, there seems to be a constant struggle between parents and professionals which were mentioned as being part of 'the system'. Unfortunately,

due to the restricted word count, this issue could not be explored in greater detail, but further research around this area may be of great benefit to both parties. Social work was one facet which was mentioned above, and it shall now be critiqued in greater detail.

4.5 Social Work

In terms of social work, the results paint a rather dismal portrayal of its application within the area of mitochondrial disease. It appears almost non-existent, with each of the participants stating they never had social work involvement. In twenty-six years of attending hospitals, respondent (A) explains her relationship with social work by stating *“I was running out of money, literally, and they sent me up to a social worker to give me vouchers for the canteen and that was the extent of my contact with a social worker”*. Having asked the hospital for a social worker, she suggests there was *“no social worker available. There was absolutely nobody available. I don’t have anybody”*. It’s clear from the discussions that parents were lacking the necessary support and guidance in adverse circumstances whilst engaging with hospital services.

Respondent (C) goes on to describe the feeling of isolation whilst questioning why there was no social work support made available. She states *“I’m on my own when I’m being told that our daughter mightn’t survive. And nobody suggested this is where a social worker needs to be”*. This is clearly a traumatising time for both mother and daughter where professional support should have been made available. Research carried out by Meehan (2017) suggested that almost 39% of participants in her study wanted to meet a social worker within 48 hours of receiving a diagnosis. Both research studies indicate a significant need for social work support where the role of social work in such circumstances should be utilised.

Interestingly, each of the participants involved in this research gave similar perspectives into the role of social work. A common theme regarding the role of social work and its misconception amongst parents was clearly depicted throughout the interviews. Respondent (B) suggests:

social workers are there, they’re in the hospital but they’re called in at the wrong times...the majority of parents see social workers as people that take their kids off them if they’re not treating them right. And a lot of the parents with very sick children who are undiagnosed because of the rarity of their disease so it’s sad that those people are treated like crazy people

Respondent (A) also has an interesting assumption as to how social workers are perceived in this country when she states that:

People see social workers as the people who come and take your kids away. You mention a social worker to a parent and they automatically assume that this person is another assessor of your mental state and that they are going to go back and tell the others (consultants) your one's a nut job.

The role of social work appears to be shrouded in a negative air of confusion, where its purpose has been analysed through a shrouded cloud of varying opinions. The perception of social work has not been helped by the negative media exposure which accompanies high profile child welfare cases. The participants share an honest opinion of the public's perception of social work. It is certainly not a helpful or positive outlook, for parents or professionals alike.

“Public perceptions that social work is primarily concerned with uplifting vulnerable children can also lead to clients de-valuing, and therefore underrating, the skills and knowledge of contemporary social workers” (Hobbs and Evans, 2017:20). In addition, Lecroy (2004) believes the negative perception of social work, may prohibit its promise as an advocate for those less fortunate or those in need of support. As a result, social workers need to advocate on behalf of their profession where role clarification and promotion of services can be understood and appreciated by service users.

4.6 Conclusion:

The findings will hopefully provide some insight into parents' experiences of mitochondrial disease and the many factors which impact them on a regular basis. A clear image of frustration and anger towards the healthcare system as a whole has been created by the parents. Many factors have shaped their views and beliefs in a system that many would say has failed them. An overwhelming sense of negativity and genuine hurt could be sensed from the interviews. The limited word count considerably reduced the descriptive scope of this chapter. Such restrictions may possibly take from capturing the true essence of emotion involved. However, it is hoped their powerful story has been duly captured through these results.

Chapter Five

- Introduction
- Research Recommendations
- Social Work Implications
- Reflective Piece
- Conclusion

5.1 Introduction

The introduction, literature review and methodology outlined in previous chapters described the proposed background and structure to the research process. Having discussed the findings in chapter four, this final chapter will include conclude the paper through research recommendations, social work implications and a reflective piece on the overall research experience.

5.2 Research Recommendations

- Medical professionals to promote a more holistic approach when treating a child with a rare disease. Such a person-centred approach would facilitate the development of the social aspect for families involved. A promotion of increased empowerment and communication would also complement this recommendation.
- A focus on improving educational modules around rare diseases. This would primarily be introduced to undergraduate and postgraduate medical students, with other care professions such as social work, occupational therapy and nursing also being offered support in delivering classes in the area. This would continue into Continuous Professional Development (CPD) once qualified
- Families suffering from a mitochondrial disease to have direct input in developing a “Mitochondrial for Dummies” style information leaflet which can be distributed throughout hospitals.
- The implementation of a ‘Red Flag System’ across all hospitals in Ireland. Children who have a mitochondrial disease can then be immediately identified upon admission to the hospital. This would alleviate some of the confusion and possible doubts which may lead to suspected FII with parents.

- Improved access to medical treatment and services for those with a rare disease. Initiatives such as the treatment abroad scheme are great in theory, but can be difficult to access, particularly when the issue is a rare disease.
- More emphasis on achieving attainable policy change which are outlined in National reports. The National Rare Disease Office was set up in 2015, to gather information and knowledge pertaining to rare diseases, as well as providing up to date treatment and management options. As of April 2018, they have no specific information relating to mitochondrial disease in the republic of Ireland. (See Appendices).
- Further research and continued collaboration with CARL may be of benefit to Mito Families Ireland. Combining this research with Meehan (2017) could provide a useful base where further study and/or publication of the combined reports could take place. Future research is needed (on a much greater scale) to raise awareness surrounding mitochondrial disease in Ireland.

5.3 Social Work Implications

The public perception of social work suggests their role is limited to child protection services and the removal of children from at-risk environments (Jordan, 2004). Research has suggested social work received its negative perception stemming back to the media coverage of historical child abuse cases. Therefore, there is a need to change public perception and inform parents what exactly a social worker does and how they can possibly offer support and information to service users. The negative perception of social work needs to change, and it must start with social work students, emerging graduates and seasoned professionals. This research and the study carried out by Meehan (2017) clearly indicates there is a need for social work intervention or support when dealing with rare diseases. The social workers could advocate on behalf of the parents and offer professional support and guidance in times of need. As a profession, social work must improve its public perception and focus on its professional role and responsibilities.

5.4 Conclusion

1. What is Fabricated/Induced Illness and how does it relate to the experiences of parents who have children with mitochondrial disease?

- Rare form of Child abuse
- Previously known as Munchausen Syndrom By Proxy
- Parent/carer fakes or causes illness
- Related to mito parents due to complexity of the disease. Parents often get the blame
- Unique relationship of uncertainty and ambiguity.

2: What factors lead to fears of suspicion/allegations in cases of children with mitochondrial disease and what are the personal/social/health implications of this concern on parents and families?

- Ambiguity of Disease
- Lack of communication
- Lack of professional knowledge/information
- Psychological and social impact
- Burden-stress-anxiety-isolation
- False allegations of FI

3: What are Parent's experiences of professional supports and services and what is the role of social work

- Non existent role of social work
- lack of respect from professionals
- Extreme frustration and anger
- Minimised and ignored
- There is a need for social work support
- Social work perception needs to change

4: How do these parents' experiences correspond with contemporary debates about user participation and empowerment in health care and social work provision?

- Parents feel marginalised
- Huge desire for professionals to increase user participation
- Implement a holistic model of care where parents are listened to

In concluding this research, a brief summary of the main research questions has been compiled in the diagram above. It gives an overview into what has underpinned the research project. From the findings, there is a clear link between FII and mitochondrial disease. The ambiguous nature which interlinks both phenomena has caused significant social and psychological issues for parents involved. As a result, the fear of allegations of FII create severe social and psychological burdens for the families involved. The parent-professional relationship has further compounded the difficulties involved in caring for a child with a mitochondrial disease. The barriers have created extreme anger and frustration amongst the parents who participated in the research. It became apparent there was no social work interaction for any of these parents, despite the suggestion it would have been helpful in times of crisis, which is quite often when managing a mitochondrial disease. Identifying the balance between the forensic/medical model and a holistic approach would promote service user empowerment within the healthcare system. Parents want to be consulted and respected, considering the vast experience they have from caring for their sick child. Overall, there needs to be changes made regarding this complex and often contested area of paediatric medicine. The voices of three parents in Mito Families Ireland have been explored and their stories have been told. The only question that remains is will those voices be heard by those who can positively influence change?

5.5 Reflective Piece:

Looking back on the research process, there is a sense of accomplishment as I sit down to write this reflective entry. My research journey began this time last year when I was attending the MSW conference, it was here where I happened to choose a presentation by Tammy Meehan, for no reason in particular other than sheer curiosity. The topic was anticipatory grief and mitochondrial disease. Prior to the conference I had never heard of mitochondrial disease and I thought nothing of attending the conference. At the time I had no indication how mitochondrial disease could be so interesting and how it could take hold of somebody's life as was described by Tammy, now I understand. After the frustrations of gaining ethical approval for the project were cleared up, it was January when the plans could be implemented. The primary research element was both a blessing and a frustration. Conversations were had between my tutor and organisation liaison person (Tammy) as to how the data would be collected. Due to the geographical locations, there were significant

logistical issues to outline and whether the interviews would be conducted over phone/skype or in person. In the end I travelled over 600 km between rural Munster and Leinster to complete the interviews and it was the single most important decision of the whole research process. Meeting the parents face to face, gave me as the researcher a platform to build a unique sense of rapport and trust that would enable the parents to tell their story. The interviews were extremely emotional, I found this difficult to process at the beginning, but it helped put things in perspective for me as an emerging social work practitioner. These parents have kids who are suffering from a life limiting disease, they live in constant fear and uncertainty. As respondent (C) states *“its always in the back of your head, it will never ever go away, ever because its life limiting. I’m always thinking will he live to 16, will he live until 18, will he live to his 21st”*. When you have a mother explaining this to you in an interview it’s difficult to process and offer the appropriate support at that time.

Once the interviews were complete, I had so much valuable information I decided to get these professionally transcribed. It would have done the parents and the research a disservice if these were not professionally converted. My only regret was the limited word count attached to this paper. The interviews provided such rich and detailed information that another 5000 words may have captured the overall story in more detail, alas, that was out of my control and I have done my best to paint a clear picture with the canvas I was given.

Looking back on the research, it was a rollercoaster of emotions, both for me and especially the parents. At the time of the interviews, I had questioned if the arduous process was worth it, if it was worth missing days of possible college work, not to mind the financial cost involved in the travel and professional transcription of the interviews. However, as I come to the end of the research, I can definitely say it has been well and truly worth it. The research experience has opened my eyes to what’s important in life, and nobody knows the suffering being experienced by people on a daily basis. The research has given me a unique perspective which I hope to bring into my personal and professional life. My only hope is the research can effect positive change and help raise awareness of mitochondrial disease.

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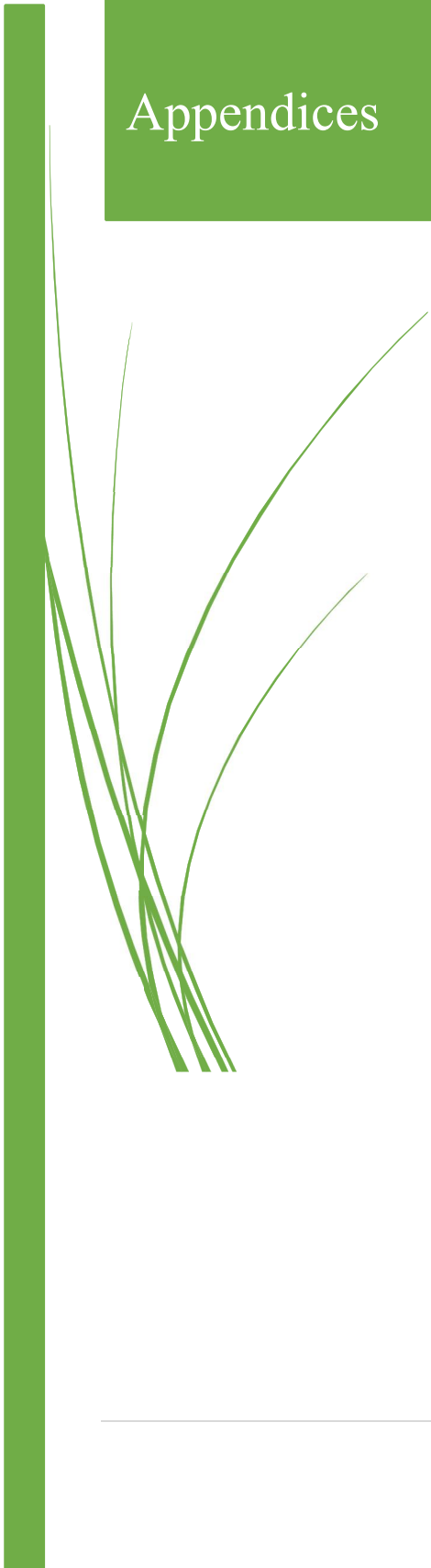
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Appendices



A: Consent from Community Organisation

B: Participant Consent Form

C: Information Sheet

D: Interview Questions

E: Email Correspondence

Appendix A



25/10/2017

To whom it may concern,

A Master of Social Worker student, Mr Phil O' Sullivan, has kindly agreed to undertake a research project that we proposed through the CARL program. The original proposal has been designed and agreed by our group and we wish to confirm that Phil has our consent to proceed with the primary research on our behalf.

We would also like to take this opportunity, as a group to thank you for your consideration of this research and thank Phil for his enthusiasm and dedication in undertaking this research. We strive to advocate for and support those affected by serious illnesses, particularly Mitochondrial Disease and Disorders, and appreciate any awareness that highlights the issues our families are faced with.

Please do not hesitate to contact us if further information is required.

Kind regards,

Tammy Meehan,

Founder,

Mito Families Ireland

Appendix B

Consent Form

I agree to participate in Phil O'Sullivan's research study.

The purpose and nature of the study has been clearly explained to me in writing.

I am participating voluntarily.

I give permission for my interview with Phil O'Sullivan to be audio recorded.

I understand that I can withdraw from the study without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one Box)

I agree to quotation/publication of extracts from my interview

☐

I do not agree to quotation/publication of extracts from my interview

☐

Signed:

Date:

Print Name:

Appendix C



Information Sheet

Purpose of the study: As part of the requirements for the Master's Degree in Social Work at UCC, I am obliged to carry out a research study. The study I have chosen will examine parents' fears of allegations of fabricated induced illness in their children. This will be from the perspective of parents involved with Mito Families Ireland

What will the study involve? The research will involve a number of participants answering a series of semi-structured questions regarding the topic in question. It is hoped the interviews will be conducted face to face where participants can tell their story. Each interview could take anything from 30- 60 minutes to complete.

Why have you been asked to take part? You have been asked to participate because this research specifically relates to the experience of families with Mitochondrial Disease. It is envisaged your input will yield positive results surrounding this research question.

Do you have to take part? There is no obligation for you to take part in this research. Participation is strictly voluntary. However, it is important to note if you do not wish to partake in the research once completing the interviews, you must inform the researcher within **two weeks** of completing the interview.

What will happen to the information you give? The data will be kept confidential for the duration of the study and will be made available to me and my research supervisor only. It will be securely stored on a password protected drive to which only I will have the encrypted password. Upon completion of the project, the data will be retained for a further 10 years and then destroyed.

What will happen to the results? The results of the interview will be presented in my final thesis submission on April 21st. The study also has the possibility of being published in a research journal and on the CARL website, which would make it accessible to anyone who wishes to read it. It is envisaged, as a CARL project, Mito Families Ireland may be able to use the thesis to raise awareness for their particular organisation.

What are the possible disadvantages of taking part? Participation in the interview may cause some emotional distress as the issue may be sensitive to those who take part.

What if there is a problem? If you feel distressed as a result of the participation, please feel free to contact me on 083 8822229 and at 116221200@umail.ucc.ie or discuss the issues with Mito Families Ireland representative Tammy Meehan. If you feel the need for professional help, please contact your G.P.

Who has reviewed the study? As a CARL project, approval must be given by the CARL panel as well as the Research Ethics Committee in the Department of Applied Social Studies, before research like this can take place.

Any further queries? If you have any further queries, please feel free to contact me: Phil O'Sullivan at 116221200@umail.ucc.ie

Appendix D

Interview Questions:

1. Can you tell me about how mitochondrial disease entered into your life?
2. What does “mitochondrial disease” mean for you?
 - What is your understanding of the term “Fabricated Induced Illness?”
3. Can you tell me about your experience of parenting a child who suffers from mitochondrial disease?
 - Challenges/positives
 - Emotional impact
 - Physical/mental impact
 - Financial
4. What has been your experience of accessing and availing of services related to mitochondrial disease?
5. What is your opinion of the parent-professional relationship?
 - Good/bad?
 - Available?
 - Sustainable?
 - Professional, knowledge based
 - Who did you meet?
6. What was the response of professionals prior to your child’s diagnosis?
Belief/disbelief
7. Do you believe professionals involved with a suspected case of mitochondrial disease are risk averse in terms of making a clear diagnosis? That is, are they are hesitant to make a decision due to the vagueness associated with the disease?
 - Why may this be the case?
 - Unclear symptoms?
 - Afraid to give solid diagnosis?

8. Can you describe the emotions involved when dealing with professionals who may not have the adequate training or knowledge to provide you with clarity and answers to your questions?
 - Frustration?
 - Anger?
 - Concern?
 - Nervous?
9. It has been suggested that parents are often forced to become “the expert” in cases where mitochondrial disease is present.
10. As a parent, do you feel you have added responsibility discussing mitochondrial disease with professionals, given the rare and complex nature of the disease? How does this impact you as a parent?
11. Were you apprehensive that professionals might have been concerned about your credibility?
12. As a parent, is there is an automatic fear regarding false allegations of fabricated induced illness? Is there a stigma attached to the topic, particularly when dealing with mitochondrial disease? Why may this be the case?
 - What are the factors?
 - Child protection issues?
 - Lack of professional knowledge?
 - Lack of information?
13. What are the effects of such false allegations? How do these impact on you as a parent?
 - Psychological trauma?
 - Emotional?
 - Can the child be affected?
 - Pursue legal action?
 - Seek different opinions?
14. In your opinion, what role has social work played in your experience with mitochondrial disease? From a parent’s perspective, what can be done to improve this aspect of service provision?
 - Was it different to other professional experiences?
 - Good/bad?
15. Is there anything which has been left out that you would like to discuss? How would you summarize your overall story involving mitochondrial disease?

Appendix E

